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ABSTRACT

This report discusses a 3-year project to examine and develop agency structures to implement a more person-centered design in Minnesota agencies assisting individuals with disabilities. Five of the eight participating agencies offered residential services; two offered vocational, employment, and day programs; and one offered both residential and vocational services. The project utilized an agency change model developed by John O'Brien and Connie Lyle O'Brien called "Framework for Accomplishment," which is based on the principle that the purpose of human services for people who require long term support is to help people discover and move toward a desirable personal future. Valued experiences for people with disabilities were promoted in five accomplishment areas: (1) sharing ordinary community places and activities; (2) growing in a wide variety of personal relationships; (3) being treated with respect; (4) making meaningful choices; and (5) having opportunities to contribute. As a result of the project, positive changes occurred for individuals, including: developing friendships, moving to their "own homes," getting more productive jobs, joining various clubs and organizations, and starting self-advocacy groups. Agency changes included revisions in the annual planning process for individuals, policies, procedures, job descriptions, staff orientation, and staff training. (CR)

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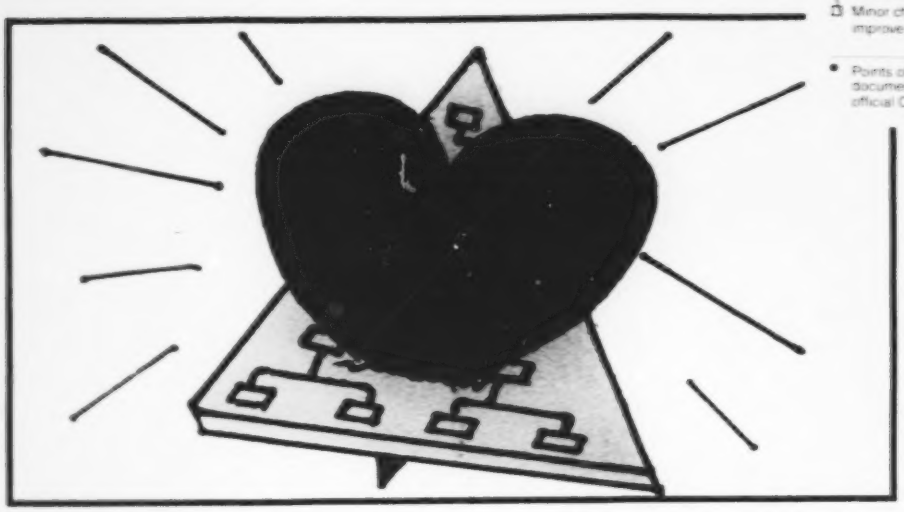

PERSON-CENTERED AGENCY DESIGN

A THREE YEAR PROJECT 1991 - 1994

HUMAN SERVICES RESEARCH
& DEVELOPMENT CENTER

1195 Juno
St. Paul, Minnesota 55116
(612)698-5565

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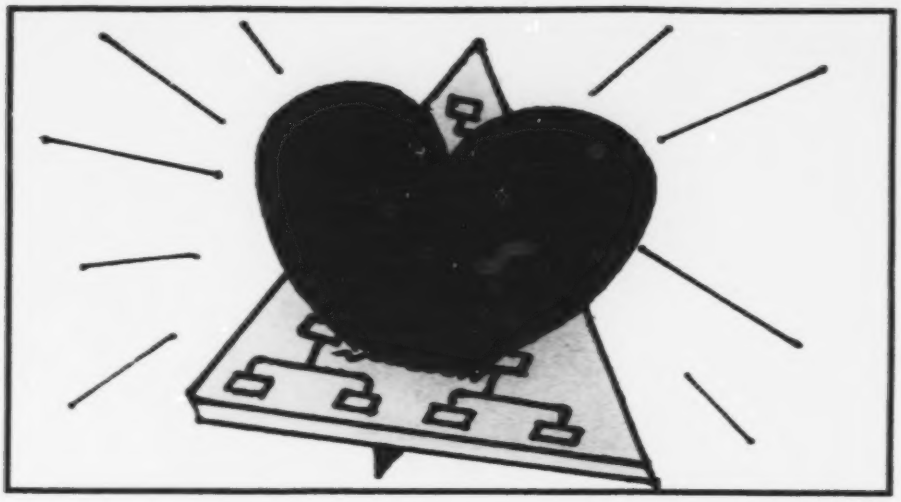

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A NEW BEGINNING

It was easy for Mike to name what he didn't like about his life. Mike didn't like his small low income apartment. It was cluttered: no room for hobbies and the fact that rent was paid out month after month with nothing in return was unspeakable. He didn't like working at the Sheltered Workshop - "I've worked there ten years too long," he said. Mike also didn't like his social life, doing the same activities with the same people on the same night every week.

On November 27, 1993, Mike moved into his own home, which he purchased through a "contract for deed." (We had asked a local person who owned a lot of housing rental property if he would sell it to Mike, and he did.) When I visited Mike in his own home, he described his feelings of being a homeowner. "Owning my own home means freedom. I can do what I want. I don't feel trapped anymore. I have space, a place to put my belongings and room to work on my hobbies. This is important to me. My neighbor stopped over and asked me to sign a petition. He said my vote counted. I feel proud to be part of my neighborhood." Being a part of a neighborhood means friendship, sharing, feeling connected. "My tree blew down in a storm. I asked my neighbor if he would cut it up for me. He did. I gave him the wood for his fireplace.. It feels good to get help and to share. My neighbor, Lenard, came over and asked if I would take a chimney pipe down from the side of my house. He said he was afraid it may fall on his house. I did. He told me anytime I need help to call on him. It's nice to finally have a good neighbor. Lenard is a friend. It's nice to be cared about - to help out - to belong.

Mike is a member of "The Sertoma Club." This "Service to Mankind" club has a lot of business owners, doctors and lawyers. Like other group members, Mike has been networking with his fellow club members. He asked a lawyer to prepare the deed for his house, and he also needed an electrician, so he asked another member.

Each Wednesday, at 7:00 AM, Mike can be found at his Sertoma Club meeting at a local restaurant. The Sertoma Club participates in the "Adopt a Highway" program in the community. Mike's had his turn calling and reconfirming members when they're set up to clear their section of the roadway, and also fulfilled his turn to bring the beer and pop. Mike says, "I feel important here. I feel I am liked for who I am. I help out and contribute my dues and time just like everyone else. I am equal here. Most of all, I feel like I am one of the guys. We laugh and kid around together." Mike was elected Sergeant of Arms in June 1994. This was the first time a member this new to the group has ever been elected to an office.

After a one year probation, Mike was hired as a full-time employee of a local company - a research firm that tests feed. Mike beams as his employer talks about his skills: "To be a lab assistant one needs a good memory and to be precise. Mike has these skills." Mike's statement about his new job portrays his feelings: "I won't do anything to jeopardize this job." Mike works around Ph.D.'s and doctors all day, and one day they all went golfing together.

Also Mike's always had a dream to have his own business. He bought a lawnmower to start a lawn mowing business. When it broke, he bought a second one.

Mike felt proud when his peers voted him in as president of the new Self Advocacy Group. As he spoke on a transportation issue to the City of New Ulm's Human Rights Commission, Mike stated it felt good to be listened to. "I feel like I'm a citizen and that my ideas and efforts count."

We'll see what the future brings for Mike . . . . . .

Sue Wojciak, MBW Company, New Ulm

PERSON-CENTERED AGENCY DESIGN PROJECT

BRIEF SUMMARY

Many criticisms of "the system" and "services" reflect the failure of human services to meet the true, human needs of individuals who are dependent of that system. Many staff think or act like successfully meeting all policies and rules is more important than the quality of life of the individuals they serve. Individual needs are often only seen or understood inside of bureaucratic definitions. Under the overwieghted burden of rules and regulations, paper requirements, funding restrictions, and operating practices, the individual lives of people with disabilities are often sacrificed, and communities are cut off from the contributions of citizens with disabilities.

Many concerned and committed professionals are aware of these weaknesses, would prefer to operate services differently, but lack the structured methods to do so. Many factors make change difficult.

BUT . . . HOW DO WE DO IT?

In 1991, eight Minnesota agencies who believed in this direction began a structured journey toward discovering how a "person-centered agency" would be designed, and worked on implementing that design. In a three-year project sponsored by the Human Services Research and Development Center (funded by the Bush Foundation and the Hugh J. Andersen Foundation), these eight residential and day program/supported employment agencies in both rural and urban areas have learned many valuable, useful, and concrete lessons. Many people's lives have altered dramatically, and these agencies have made significant changes without waiting for additional funding or changes in regulations. It was the first time a group of such agencies has come together for this purpose, and the variety among the agencies and their different paths has also provided much information on the process of organizational change.

The project operated from September, 1991 to September, 1994, and its purpose was to examine and develop agency structures to implement a more person-centered design. These were the participating agencies and the different parts of the state in which they are located:

- Clay County Diversified Services, Inc./
  Supported Training Services in Moorhead (northwest)
- Cooperating Community Programs (CCP) - Washington County (metro area)
- Dakota, Inc. (metro area)
- Houston County Group Homes (southeast)
- International Falls Group Home (Lutheran Social Services) (northeast)
- Linnea Residence in Chisago City (east central)
- MBW Co. in New Ulm (south central)
- STEP, Inc. in Fairmont and Blue Earth (southwest)

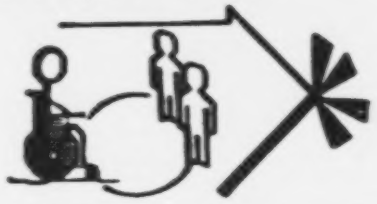
Five of these agencies offer residential services, two provide vocational, employment, and day programs, and one offers both residential and vocational services.

The project utilized an agency change model called "Framework for Accomplishment" (1990), authored by John and Connie Lyle O'Brien. This model is based on the principle that there are three purposes of human services for people who require long term support. The purposes are on the next page:

The Purposes of Human Services for People Who Require Long Term Support

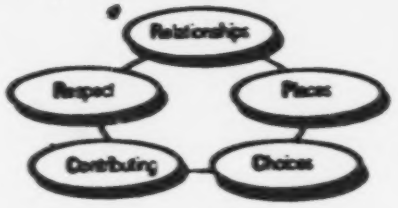
To help people discover and move toward a desirable personal future.

- Discovering a vision.
- Creating opportunities.
- Delivering support.



To offer needed help in ways that protect and promote valued experiences now:

- Growing in personal relationships.
- Sharing ordinary community places & activities.
- Contributing
- Making choices.
- Being treated with respect and having a valued social role.



To offer needed help in ways that support and strengthen community competence:

- Supporting family and friends who care.
- Strengthening links to community networks.
- Expanding membership in community associations.
- Increasing the openness of the local economy.
- Improving the effectiveness and inclusiveness of services and benefits available to all local citizens.

From John and Connie O'Brien's Framework for Accomplishment: A Workshop for People Developing Better Services, 1991

A five-day self-analysis of each agency was completed in the first 6 project months using the 5-day Framework for Accomplishment workshop.

After these initial analyses of each agency, each of the eight agencies worked with staff of the Human Services Research and Development Center (H.S.R.D.C.) to implement constructive actions and methods over the course of the three years of the project. People involved included the individuals with disabilities, parents, board members, direct care, management, county case management, and state Department of Human Services staff.

Over the course of the project, many positive changes occurred for individuals with disabilities. These included people starting new friendships, moving into their "own homes," having more productive jobs, volunteering in their communities, joining various clubs and organizations, and starting self-advocacy groups.

Agencies also changed the way they operate. Examples include revisions in the annual planning process for individuals, policies and procedures, job descriptions, and staff orientation and training. One 8-bed group home closed. A day program moved to entirely closing its segregated day facility and having all persons either in employment or in integrated community opportunities. The planning process, team and staff meetings have been changed to focus on desirable futures, dreams and visions for people's lives, and staff actions to assist people in moving toward those futures. As agencies became more person-centered, they also looked at closing or downsizing larger programs, impacting the other provider agencies with whom they work, and getting their local communities more involved with the people they support.

There have also been meetings and discussions with various county and state officials to develop a more person-centered "system" to support people with disabilities. Some of the elements of such a system include a more person-centered approach to annual planning, more flexibility in funding, person with disabilities having more control over their service dollars, more home ownership, and smaller, more individualized living situations.

RESULTS OF THE PROJECT

Changes For Individuals

Human Services Research and Development Center monitored the progress of the fifty-three focus individuals in the project every six months through Individual Change Report Forms that were completed with the assistance of staff who work directly with the individuals.

There was significant progress toward more desirable futures not only for the fifty-three focus individuals, but also for many other individuals supported by the eight participating agencies. More people are living in their own homes and have their own personal space; more people have jobs that match their unique skills and interests; and more people have developed friendships in their communities and are contributing members of a variety of organizations.

Some specific examples include:

- Six individuals have purchased their own homes.
- Several people with physical disabilities are now living in truly accessible apartments.
- Many individuals have reestablished relationships with family members (in some situations there had been no family contact in over 10 years).
- Individuals have joined organizations such as the Sertoma Club, Arthritis Support Group, volunteer fire department, TOPS (Taking Off Pounds Sensibly), Women of Today and a variety of church groups.
- Individuals are volunteering at nursing homes, thrift stores, programs for animals, as a Big Sister, and in other community programs.
- One couple recently were married.
- One woman hosted a Tupperware party.
- Two women participate in line dancing weekly at a local nightclub; one was paid to help teach a line-dancing class.
- One woman became a Board member of a local recreation program.
- Many people have joined self-advocacy groups and are speaking for themselves more and more loudly.

Agency Changes

The eight participating agencies in the project have developed person-centered agency goals. Human Services Research and Development Center staff have assisted the agencies in developing and implementing these goals, and progress was documented annually through the Agency Change Report Forms which were completed at agency annual planning meetings. Agency change efforts were focused on incorporating person-centered methods into ongoing agency processes, and changing the fundamental nature of many agency processes.

Agency changes have included a more person-centered approach to annual individual planning; revisions of mission statements, job descriptions and staff orientation; increased efforts to train, motivate and empower staff; and more communication with counties and other providers.

Some specific changes for the agencies include:

- Several agencies have initiated major changes in the preparation and format of the individual annual planning process, supporting the person to run their own meeting, encouraging more individual/family involvement in the content, location and personality of annual meetings, and a greater focus on desirable and individualized personal futures and valued experiences.

- Mission statements, job descriptions and staff orientations have been revised by several agencies to reflect a more person-centered approach, emphasizing O'Brien's five valued experiences.
- Three agencies, with assistance from HSRDC, have developed self-advocacy groups. Self-advocates have discussed many important issues, and with agency staff assistance, have presented their feelings to a sheltered workshop about work conditions and to a Human Rights Commission on problems with transportation.
- One agency included three individuals they support on the agency softball team in a local recreational league.
- Several agencies have changed their staff meetings to encourage more discussion on individual desirable futures and how staff can assist people in community connections, and have developed other ways to integrate a focus on person-centered values and goals into existing agency processes.

System Impact

Participating agencies have been able to make "internal" person-centered changes, and attempted, with some success, to impact the entire system that is involved with the individuals they support. Some specific efforts include:

-One agency closed its 8-bed group home (ICF-MR).
-One day program moved to entirely close its segregated day center, and have all individuals in employment or integrated community options.
-Two other residential agencies have had serious discussions with county and state officials concerning the closure or downsizing of their larger (ICF-MR) group homes.
-Agencies have developed better working relationships with other provider agencies by meetings with key staff, presentations at staff meetings (with HSRDC's assistance) and specific discussions affecting individuals.
-The improved relationships helped create the atmosphere to change the annual planning process. Participating agencies in the project, other provider agencies and county case managers have all been involved in creating a more person-centered approach to annual planning.
-Several agencies have met with county and state officials concerning licensing requirements. Agencies have requested and received variances of some rules to allow individuals more control over their lives, while using a common sense approach concerning risk-taking and vulnerability.

Changes In The Community

As the participating agencies changed the manner in which they operated, more emphasis was placed on the the individuals they support having integral roles in their communities. The response by communities to agencies and individuals has been positive in many situations. Examples include:

-Many community members have befriended individuals who receive services.
-One realtor/developer has provided more rental and purchase options for individuals supported by one agency. He has willingly made accessible adaptations to rental property, and will hold a contract for deed to allow an individual to purchase a home.
-One large employer highlighted an individual supported by one agency in the employer's newsletter. Other individuals supported by other agencies have also been featured in local newspapers and company newsletters.
-Community education programs and community associations in many locations have included individuals in their regular classes and meetings, and have willingly provided the necessary accessibility components.

SUMMARY OF PROJECT PROCESS

Framework for Accomplishment

For each of the eight participating agencies, a "Framework for Accomplishment" (O'Brien & O'Brien, 1990) five-day workshop was completed as a self-evaluation. Each agency team was composed of four to twelve staff and included direct care, program directors, and upper management. Some teams also had a county social services employee or staff from another agency (day program or residential).

For the workshop, a small group of people (ranging in number from four to twelve) who receive services from the agency was selected for focus. The eight agencies selected a total of 53 focal individuals. For each of these focal people, a "Personal Profile" was completed. This profile consists of several sections, such as history, relationships, preferences, gifts, etc. and draws on areas similar to Personal Futures Planning. The two-person team completing this profile spent time with the person in their day and evening settings, interviewed people who knew them, and tried to understand their life from the perspective of the five valued experiences and a desirable personal future.

On Day 3 of the workshop, all profiles were brought together and presented to the whole agency team. Overall impressions of the five valued experiences were rated for the focal people. A summary was made of "What's Most Important Now" for the individuals who receive services. Sample issues included:

1. Being valued as individuals
   - starting with staff
   - by community members
   - by everyone, families, perception of agency, etc.

   "get to know me"

2. Freedom, independence, self-determination

   "Having the say in your life"

3. Real jobs and money

4. Relationships and friendships
   - more intimacy

On Day 4, the agency processes were analyzed. The team identified what the agency was doing that increased each of the five valued experiences and what decreased the five valued experiences. A summary was made of the "Key Developmental Issues" for the agency -- what it needed to develop the capacity to do in order to fulfill "What's Most Important Now" for the individuals who receive services. Sample issues included:

1. Shift the way the agency interacts with the community
   - listen to community better
   - have community members get to know people
   - make community connections a higher priority

2. Design around Futures and Dreams
   - walk with people as they take control of their lives
   - develop people's capacity to speak for themselves
   - help represent people's interests: home, jobs, etc.

3. Look at how people can make individual contributions
   - push more for being included in regular stuff
   - filter into clubs (staff filter in, too)
   - focus more on what people have to offer

On Day 5, each two-person team created a story about their focal person's life a year in the future and what had happened over the course of the year to have a better future realized in that year. The story included constructive actions that were taken by specific people that helped make real more of the desirable future a year from now.

Backward Planning

Within a month or two after the 5-day workshop was completed, another process called "Backward Planning" was completed with each agency team. This process was based on a method described by Russell Ackoff and used with businesses and corporations (Management in Small Doses, 1986).

A graphic analysis of the relationship between three elements -- the agency, the individuals served, and the community -- was developed by each agency. These symbolic representations portrayed the understanding of the existing relationships between those three elements. Then a second graphic was completed -- of the vision of what a person-centered agency would look like, and how the relationship between those three elements would be in that desirable future for the agency.

A time-frame was set for this "desirable future" being realized -- fifteen to twenty years. Then the group worked backward: if that was the goal in twenty years, what had to be accomplished in ten years? in five years? in three years (project-end goals)? in one year? The one-year goals provided tasks and objectives for immediate action. Samples of 3-year goals included:

Close one ICF
75% of people through Personal Futures Planning
Alter annual process
Two more people own their own home
Five people have friends
Everyone have solid connections

Experiment with creative ways to use people's money
Everyone understands the person as Personal Profile reflects
Staff see role as community connectors
More meaningful jobs and experiences

Ongoing Work

Each agency met with HSRDC staff approximately once a month. In these meetings, progress toward identified goals was shared. Plans were made to address problems, implement strategies to realize goals, and provide more training.

We had several project-wide meetings for all eight agencies together:

1. August 1992, end of the 1st year -- all eight agencies shared the results of their 5-day workshops and their plans for the future.

2. October 1992 -- meeting with John O'Brien to receive training and plan directions in implementation.

3. June 1994 -- two day meeting with John O'Brien to summarize lessons learned from the project and recommendations to state government.

4. July 1994 -- project-end statewide conference to share results of project. Approximately 250 people attended from three states and one Canadian province.

INTERNAL STRUCTURES FOR A PERSON-CENTERED DESIGN

The agencies in the project developed many specific alterations to design services around better futures, the five valued experiences, and empowering community members:

I. Understanding a person better and supporting a desirable personal future:

(a) specific methods (e.g., Personal Futures Plans, Personal Profiles from Frameworks for Accomplishment, etc.) for staff to understand a person with disabilities in more thorough, value-based ways

(b) annual planning and other formal planning processes focused more on desirable futures and the five "valued experiences" of socially valued roles, relationships with community members, contribution, community presence, and choice

(c) alignment of direct-line staff and others regarding a desirable personal future for an individual

(d) focus of staff meetings around the desirable future and valued experiences for individuals --progress over time, new ideas on fulfilling that future

In realization of these more desirable futures, some of the elements of change in the agency and system included:

- staff making personal commitments to introduce individuals with disabilities to their family and friends, live with individuals, find long lost family, etc.
- arrangements for funding being made for other living situations
- types and degree of community businesses employing individuals, and types of employment

II. Promoting community membership and participation, contribution, and valued roles:

(a) redesigning staff time so that individual staff spent time supporting a person in one-to-one connections with community members and in fulfilling more highly valued community roles

(b) support by job coaches of relationships with nondisabled coworkers --job coaches putting more emphasis on relationships with coworkers

(c) helping people join associations and clubs

(d) helping people volunteer in situations with nondisabled community members

(e) strengthening relationships with family members
(tracking down other relatives such as siblings; inviting families to lunch and informal gatherings especially if they had not attended formal meetings in years; sending photos, cards and letters, etc.)

(f) staff asking persons in their own social networks to get to know or spend time with individuals who receive services

(g) going to same places of business regularly -- restaurants, hair salons, banks, local stores, etc. -- where same community members work over a long period

(h) staff being assertive, such as asking community members who seem interested in an individual if they would like to get together for coffee

III. Promoting independence and choice:

(a) supporting people buying their own houses

(b) supporting the establishment and continuation of self-advocacy groups

(c) learning to listen better to the preferences being expressed

(d) determining what kind of life each person wants, and taking steps toward a life of meaning for that person

IV. Gathering support from others in the system:

(a) aligning with other agencies (county case management, other providers) and families around desirable futures

(b) working to creatively solve the problems that arise from making vision real - such as seeking waivers and exceptions to rules, seeking additional funding for needed support, and determining how to put more financial control in the hands of consumers

ANNUAL MEETINGS

Many of the agencies altered their formal annual plánning process to be more person-centered and based on identification of preferred futures. The principles and content for these meetings included:

I. PHILOSOPHY

A. Consumer Choice

1. Content
2. Location (holding meetings some place "fun" and preferred by consumer)
3. Leadership (consumer runs meeting as much as possible, with us supplying needed tools)
4. Format - what format and content would consumer choose to discuss their life and plans?
5. Respecting individual dignity - discussing other subjects or "hot topics" outside of or before meetings
6. Attendance (including direct care staff) - who does consumer want?
7. Frequency of meetings - what makes sense for this individual?

B. Respect and inclusion of all members' ideas

II. CONTENT

A. Individually designed around the person

1. Pictures, wish lists, posters, etc.
   (a) posters regarding capacities, wishes, dreams
   (b) if the person doesn't communicate verbally, providing an opportunity beforehand to select and make a poster of magazine or other pictures that reflect wishes and dreams (or finding other forms for that person to express personal preferences)
   (c) a "wish list" - blank poster posted at home to gather casual expressions of wishes expressed throughout the course of day-to-day living
2. Focus areas reflecting five valued experiences (relationships, choices, etc.)
3. Avoid standardization - each meeting should reflect that person's personality

B. Future Oriented

Start with desires and dreams - then goals represent a means to an end, or the fulfillment of desires and dreams rather than a focus on deficits (for example: personal profiles, futures planning, etc.)

C. Celebrations

Some meetings, such as semi-annuals, set aside as opportunities for celebrating the person and their accomplishments (no papers).

III. FORMALITIES

1. Mail out and review paperwork before the meeting rather than rehashing the past year at the meeting
2. Call with questions ahead of time
3. No reading aloud allowed
4. Reports - - consumer has their own set of papers

FACTORS CONTRIBUTING TO ORGANIZATIONAL CHANGE

Several different factors seemed to be at play in the agencies that experienced more change and, within an agency, in the areas in which more change occurred. These factors included:

1. Commitment by leadership
   --involvement of top management and Program Directors
   --leadership at both the Executive Director and Program Director level
2. Perceived capacity for change
3. An atmosphere of creativity
   --bringing it and encouraging it in others. This was especially critical on the part of the Program Directors and Program Managers.
4. Support by county
5. Support from families and board
6. Staff crossing their own social networks to community
   --helping to establish relationships with community members and helping people join community associations
   --the agencies in which staff were willing to link in their own social networks were more successful
7. Energy of new staff
   --after agencies had changed their mission statements, job descriptions, and orientation training, new staff came into a different environment and could bring fresh ideas

FACTORS WHICH SUPPORTED SUCCESS

The agencies themselves identified the following factors as contributors to their successes. This is a comprehensive list from all eight agencies - not all factors applied in all cases.

1. Cooperation of county
   (a) support of county case managers
   (b) county involvement in original Frameworks team
2. Strong support from leadership
   (a) direction in which the agency already wanted to be headed; direction in which owners and/or board were committed
   (b) a strong tradition of "good services" and systematic planning
   (c) board support
   (d) strong parent leadership
   (e) commitment of regional supervisory staff
3. Highly committed staff
   (a) already strong philosophical base
   (b) a strong tradition of "good services" and systematic planning
   (c) committed program directors
4. Strong community support
   (a) large number of metropolitan area businesses with long-standing affiliations
   (b) openness of community businesses to hiring supported employees

5. Staff willingness to bring people together
   (a) staff personal contacts in relatively small towns
   (b) staff willingness to involve their own social networks in people's lives
6. Systematic organizational approaches such as rewriting mission statement, job descriptions, etc.
7. Smallness of agency
8. Willingness to take risks

FACTORS HINDERING SUCCESS

The agencies identified the following factors as issues hindering progress. (This is a comprehensive list, with only some factors applying to each agency).

-- Long-tenured staff slow to change
-- More change difficult in 4-person homes than in individual homes
-- Staff ratios in 4-person homes made community connecting efforts difficult
-- Variability among several sites within one agency in leadership and commitment
-- Efforts to put more financial resources under control of person who received services difficult due to county and state reimbursement rules
-- Financial reimbursement systems for supported employees prevented workers from receiving checks directly from employers
-- Major challenge to close 12-bed home
-- Impossibility of being able to downsize ICFs and maintain financial viability
-- Founding parents/board/county commitment to maintaining group homes
-- Lack of an articulated vision on part of county
-- Perceived difficulty in getting county to do things in a new way
-- Perception that county would want staff to over-formalize efforts in written programs
-- County reluctance to exceed waiver average reimbursement in closing 8-bed home and establishing smaller houses
-- Many ongoing efforts and activities interfered with initiating new project-related activities
-- Cooperation with local group homes difficult for a day program

SYSTEM FACILITATORS FOR PERSON-CENTERED SERVICES

-- Cooperation from other agencies who support the individual; agencies working together
-- Alignment from others such as family, case manager, other agencies on goals for person
-- Individual commitment of particular county case managers
-- Commitment to this direction from county leadership
-- County and state willingness to grant variences/exceptions to rules, to be flexible
-- Support for exceptions, waiving of rules, and flexibility in individual cases
-- Support for developing more person-centered, desireable-future ways to do the annual planning and other formal planning processes
-- Support for other residential alternatives

Person-Centered Agency Design Retreat

In a two-day meeting in June 1994, the agencies summarized themes and lessons in their three years of work. The notes and discussions were summarized by John O'Brien as follows.

CHANGES WE CAN SEE FROM 1989 - 1994

In the first discussion, agency staff were asked to think about the ways in which they were operating in 1989 or so, just prior to the time we the project started. If a visitor came in, what would they see people doing, how would they see staff spending their time? Then, staff were asked to consider what was different now, what changes would a visitor see coming in now?

We have assisted people to make changes in where they live.

Most people used to live in group residences. Now:

*Some people are purchasing their own homes.
*Some people are renting places in their own names, either individually or in small groups.
*Some people are living in residential facilities which serve smaller groups.
*We no longer use people's homes as the site for agency business.
*We have moved our business out and made places more for the people who live there.
*People's surroundings reflect their choices and personalities better: color schemes, furnishings, personal things, menus, and daily routines.
*Instead of staff giving tours of agency homes and introducing the residents, people now introduce themselves (or are introduced) by name and might show a visitor around their home.
*Some people are living with people they have chosen to live with.
*Some people have married and some people have decided to live together.

We have assisted people to make changes in the ways they spend the day.

Most people used to spend the day as part of a group in a workshop or activity program or in an enclave or work crew. Now:

*More people have jobs that reflect their individual interests and abilities.
*More people have jobs where they get significant support from their coworkers, supervisors, and employers.
*We are no longer satisfied when someone is simply occupied or employed in an entry-level job, we are thinking with people about their career paths.
*More people are volunteering their time in community organizations and causes.
*Within day programs, people are more likely to belong to a smaller group, based on their interests rather than simply be part of a group based on their apparent disability.
*We no longer organize the day for people who need the most assistance around personal care routines; we attend to better understanding their interests and contributions and to providing opportunities for new experiences and for relationships.

We have helped people attain greater autonomy and choice.

*People who once were state wards have either become their own guardians or we have helped them find guardians from among their family or friends.

*Some people have organized self-advocacy groups. In one community the self-advocacy group has worked successfully to make improvements in public transportation.

*More people have control of their own money.

*People make more decisions about their schedules. Instead of dealing only with people in groups, we are assisting more people as individuals, at least part of the time.

*Some people have decided to spend less time attending special recreational activities and more time in other activities of interest to them.

*We are no longer routinely designing programmatic consequences to shape people's everyday behavior. People have more opportunity to be themselves, to make choices, and to deal with the consequences of their decisions. Sometimes people have to deal with staff disappointment or anger as a consequence of their choices.

*We are willing to deal with more uncertainty and conflict.

- Instead of just ruling things out as unsafe we are weighing the rewards associated with risk and trying to deal with risk.
- We are working to understand and deal with conflicts that arise when staff don't agree with or approve of a person's decisions.
- We are supporting people to deal with conflicts that arise when a person makes a choice with which the person's family members disagree.

*We are working to insure that people have access to communication methods and devices that are most effective for them.

*We are responding to challenging behaviors by trying to understand them as communication. This approach has lead to new responses; for instance, instead of receiving a program to decrease problem behavior, a person has been assisted to take dance classes and sign up with a dating service.

*We have helped people with physical disabilities to get better assistive devices. Sometimes, this has meant helping a person get a power wheel chair instead of staff organizing their work around pushing the person's chair.

*Some people have begun to represent themselves in making complaints to case managers and demands for change in the system.

*We are paying more attention to the consequences of how we see people and how we treat people regarding their self-esteem.

For example, encouraging people to learn about makeup and shop for some of their clothing in the same places staff shop (places that give people selection and personal attention) has helped some people experience greater self esteem. This increased self esteem shows in people's desires and choices.

We have aligned ourselves more with people's interests and dreams.

*Instead of talking over and around people, we focus more on listening to and talking with people.

*We focus much more on people as individuals.

*Staff assignments have shifted from assigning a group of staff to work with a group of people, to particular staff responsible to a much smaller number of people. This allows more continuity, better listening, and more flexibility for action.

*More people are in control of their own planning process. Instead of meetings chaired by staff, attended mostly by professionals, scheduled annually to comply with regulations, and reported on required forms, more meetings are led by the people concerned, attended by people involved with and invited by the person concerned, scheduled more often in order to deal with issues that come up from making changes, and recorded on posters and in a flow of cards, personal letters, and pictures. Meetings have become more personal, more flexible, and much less predictable.

*We focus much less on people's deficits and much more on people's interests and abilities. Formal assessments matter less and images, dreams, and hopes matter more.

*We think of our goals with people much less in terms of independence (understood as doing things alone) and much more in terms of interdependence, mutual care, and shared work and activity. This means that we don't see ourselves so much as taking care of them, as we experience ourselves sharing projects and daily experiences and looking for ways to make these experiences mutually interesting and rewarding.

*Some people have made an important shift from "what are you going to do for me" to "what can I do and what will you do so that I can achieve something that matters to me."

*We are less oriented to staff convenience and more ready to try to figure out ways that we can help people. Many staff are finding themselves working across traditional program boundaries and at different hours (and sometimes for more hours) than they used to.

*The standard for judging staff performance has shifted from the greatest reward going to staff who did the best job of complying with regulations to a greater appreciation of staff who are actively involved with the people they support.

*The system we are part of can be very demanding, but we have learned that if we stop organizing our activities just around surveyors' expectations we can maintain ourselves as an agency, make a difference to people, and have fun.

*We feel more confident in encouraging people to dare to dream and to see the world as open to their desires if they are willing to give their dreams a chance.

We are helping people to belong.

*More people are members of community groups (like Women of Today, Sertoma, sports leagues, and the Y).

*Our plans used to be about teaching people to do laundry and cook. Now they are about finding friends and getting involved in community activities.

*We are helping people to invite others to be involved in their lives.

*We have come to see ourselves not only as teachers of people with disabilities, but also as teachers of our communities.

*We used to assume that we had total responsibility for people. Now we expect community members to take an active part and to provide some of the support that people need. This is leading to more and more shared assistance.

What We Have Learned About The People We Assist

*There is much more energy in helping people to discover and work for their dreams than in prescribing skills to be learned.

*When we shift our relationship to people, their ability to communicate, be involved with others, and develop ways to move toward their dreams changes. If we focus on deficiency and assume helplessness, people will develop very little. If we push away helplessness and deficiency, and affirm people's dreams and desires by joining them, important changes will happen, unpredictably.

*We have to build trust. Some people and families have said what they want before and there has been no follow through. Some people and families have been treated very negatively.

*We become trustworthy a bit at a time when we listen, acknowledge what people tell us, develop shared commitments to action, and follow through on our commitments.

*Some people communicate much new information when we spend individual time with them, try new things in different places and attend to their nonverbal messages about what they like and don't like. A person doesn't have to have verbal language to share their interests and abilities.

*We have to not only listen to people's thoughts and perceptions, but have to be sure that they know that we are listening. Sometime solutions flow from listening. This is as true for family members and staff as it is for the people we assist.

*Change does happen, but significant changes can take time. And, to build trust and confidence, it's important for people to see and feel something happen. One way to deal with this paradox is to make sure that the ultimate goals stay clear and then agree on very small steps toward it. We can celebrate each step even as we acknowledge that we aren't there yet.

*It helps to keep people's visions alive and renewed. The posters that capture people's images of a desirable future should be regularly reviewed. Often people will want to add to them or revise them. When people know we are more interested in their vision as it develops, than in one expression of it, some people will find greater energy.

*The results of our planning and our work may be different from what we expected. Sometimes the results are better than we expected.

*In order to feel meaning and satisfaction, people need to give and exchange, not just take help.

*Some people still have no one to be the keeper of their personal stories. One of us may be the only person in a position to know the person's history. We each need to be aware when this is so and careful with the responsibility.

What We Have Learned About The Relationship Between The Community And The People We Assist

*Something very different happens when we go into community situations with "my client" than when we go into the community with "my friend." The person is different, I am different, and the community members we meet respond differently.

*It's important to look for roles that link people's interests with opportunities for relationships with community members. Jobs developed based on individual interest can create such links. So can memberships in community organizations. So can volunteer roles.

*Ordinary routines -- shopping, getting a hair cut, or banking -- can create positive connections. We can help people locate places where their regular participation will matter: where it might be more important to keep coming back than to use a coupon to get something cheaper somewhere else.

*Some people seem to be able to make their own connections if we stop being over-controlling and help people in practical ways.

*Other people benefit from the company of a "connector" -- a person who purposely helps relationships get started and then steps back. It is hard to know who will be an effective connector. Personality seems to be involved, so does knowledge of community, so does knowing lots of people, but none of these things are certain predictors. For now, it's important for people to try and see if they have this gift.

*Resistance will happen -- from community members, from parents, or from people themselves. Resistance can be the beginning of a stronger relationship if we recognize it, acknowledge it, and negotiate with people about their concerns rather than walking away feeling superior and frustrated. For example, if parents are concerned about safety issues, it's important to communicate respect for the parents and get actively involved in working things through.

*There are many people in communities who will open their doors and get involved if we knock and invite them. But many people are too busy or disinterested. If we are turned aside by "no's" instead of using a "no" as a reason to ask the next person in order to find a "yes," people will remain isolated.

*Many people need clear, honest information and are glad to have their questions answered.

*There are real differences between communities and neighborhoods. Our stance toward communities must mirror our stance toward people. We have to look for capacities and think about how to support their development and expression. Interested members of communities and neighborhoods can learn from what has worked in other places.

*There is widespread concern about the breakdown of families, neighborhoods, and communities. This makes our concern for building community even more important. We need to find ways to encourage things that will make our communities better for everyone. We need to look at what we do in terms of a wider community agenda. Affordable housing and good public transportation will benefit many people and open up opportunities for working with other concerned people.

*It takes a great deal of energy, belief, and commitment to walk side by side with people. There are many rewards in giving yourself to another person, but sometimes what happens to people can be heartbreaking.

What We Have Learned About The System And Ourselves As Part of It

The system we are part of does not make the kinds of changes people need easy. Despite interest and sympathy from system leaders as individuals and, to some extent in their formal roles, we don't believe that change will come from the "top down." We have to organize ourselves to deal with forces that come down on us and with forces that pull us from side to side. (The quotation marks acknowledge that one fact about the system is that we see and organize it with a "top" and a "bottom," with people with disabilities on the "bottom.")

The pressures that come from "above" include:

*The system is built on, and enforces through its routines and regulations, an approach based on classifying and fixing people.
*The system sends mixed messages: its leaders talk about valuing person-centered work but still holds agencies accountable to regulations that are inconsistent with a person-centered approach.
*In many situations it seems that funding issues come first. For example, in one situation, work to change people's living arrangements to match their individual plans resulted in the county creating a competition based solely on cost. This almost led people to lose their service relationship with people who know and care about them. In this competition, person-centered response counted for nothing; price counted.
*Funding streams are rigid and program-centered.
*Some counties further restrict funding streams by imposing additional conditions or cutting rates beyond state guidelines.
*Though many people agree that better services depend on working to "satisfy the customer," many different people claim to be the customer: state and county funders, inspectors, and family members all have a claim on being "the customer." It is challenging to focus on the person first in this situation.

To deal with "downward" pressures calls on us to . . .

*Persevere in making the next important thing happen for the next individual.
*Negotiate actively, creatively, and courageously for exceptions to rules that get in the way.
*Look for ways to find exceptions that benefit everyone.
*Share the stories of what's happening for individuals.
*Identify the effects of policies and rules on individual people's lives.
*Work politically at the county and state level.

The sideways pressures include. . .

*Communicating and coordinating with other agencies that the person relies on.
*Coordination is especially difficult when other agencies have different goals and different understandings of who the person is and what the person needs.
*These splits can occur within our own organizations, too.

The best ways to deal with these sideways pressures include. . .

*Stay actively involved with people in other agencies.
*When important differences exist, keep looking for ways to bring the person into the focus of discussion and decision-making.
*Look for opportunities to work together, such as co-written grants and joining in shared training.
*Acknowledge any "cause for applause."
*Sometimes the involvement of a third party changes a relationship. In one situation, the active involvement of county case managers in person-centered planning gained the participation of providers who had previously been unwilling.

The way we organize ourselves can make available resources more flexible.

*When managers set parameters and support decision making by staff who work closely with people, the organization gains flexibility and builds confidence in staff.
*Hiring practices are important. It seems easier to train skills than to deal with trying to change people's attitudes. Carefully defining core competencies and attitudes, and involving staff in hiring the members of their teams, decrease the chances of internal splits in focus and attitude.

What Would We Like The People With Responsibility For Managing Our System To Hear And Act On?

Themes

* The tension between being accountable to the people we assist and being accountable for our funds is increasing to the point that we often feel that the two accountabilities are in direct competition: either we are accountable to the person or to system managers. This is a situation which can only be dealt with if we avoid blaming and find ways to rethink these issues together.

* The state-level division of responsibility between DHS and the Department of Health is one significant factor in generating this destructive tension. Department of Health imposition of a medical model, through processes that focus on compliance with procedures justified by concerns about physical safety, distorts our work and greatly limits the freedom of the people we assist.

* Given limited funds, we will achieve more for people if we work creatively together than if we divide ourselves into "top" and "bottom."

* The existing pattern of funding has generated many inequities and wasteful irrationalities. For example . . .

  . . . a person has different kinds and amounts of resources available depending on where the person lives. Someone who lives with family has different resources for day service than someone who lives in an ICF-MR or someone who lives with the support of a waiver program. People living in ICF-MRs have access to different medical and behavioral services than people living in waiver-funded accommodations.

  . . . organizing waiver funding around institutional "conversion" and "diversion" makes the system unnecessarily complex and creates a trap. If a county has brought home all of its previously institutionalized citizens (through "conversion"), then people currently congregated in larger ICF-MRs cannot move out into waiver-supported accommodation because the only available waiver funds are dedicated to people living in circumstances that make them eligible for "diversion."

  . . . a state operated program is funded at a much higher level than a program under other sponsorship.

* The current system of dividing responsibility for people between day and residential agencies is becoming less and less relevant to our work. In many situations it has led to a kind of compartmentalization that is very time-consuming and costly to manage without offering apparent benefits to the person involved. To the extent that this division of responsibility really offers people a safeguard, we should seek other ways to provide it.

* Given the size of case loads and the limited time case managers are able to spend in contact with the people on their case loads, it may be necessary to find other ways to offer people the benefits promised by case management.

* We face a significant challenge to our creativity in devising ways that people who require substantial amounts of personal assistance (up to 24 hours a day) can live in homes of their own.

* While many people of good will claim to represent the best interests of people with disabilities, our work has shown us that the question of what is best for a person must be negotiated thoughtfully on a person-by-person basis by the person themselves and people who know and care for the person.

* While we believe that person-centered planning and orienting our work toward valued experiences offers important benefits and should be actively promoted throughout the system, we are worried about the negative effects of bureaucratizing these valuable approaches. Commitment and willingness to listen to and learn with people are essentials that cannot be bureaucratically required.

BARRIERS WE EXPERIENCED IN THE LAST THREE YEARS, BOTH INTERNALLY AND EXTERNALLY

(1) Funding
- -- rigid: need money attached to person to use as they want
- -- resources limited
- -- funding streams reflect the way we've always done it
- -- more ownership and support from community means decreased FTE for us

(2) Rules
- -- compartmentalization of individuals
- -- conflicting interests
- -- governmental turf battles
- -- advocates/parents: safety
- -- overprotective attitude of system
- -- insensitivity to the problem
- -- fear of risk
- -- being overprotective
- -- housing needs to be split from service providers

(3) We're given the opportunities and freedom to be flexible but not given the support

(4) Attitudes
- -- Other person's lack of belief in concept or no skills
  - preoccupation with peripheral tasks
- -- Staff attitude -- not being active listeners
- -- Some staff don't "own" this approach
- -- Some staff talk the talk but don't walk the walk

(5) Time
- -- Time -- too much "busy work" -- paper pushing
- -- System doesn't view as necessary -- no time
- -- Outside people reluctant to join process due to perceived time commitment

(6) Internal limits
- -- Our own creativity, our communication, our energy

(7) Change
- -- The perception that everyone already is person-centered, no need to change
- -- We don't know how to support people who don't want to be involved in person-centered work
- -- These steps involve change; change is very difficult for people
- -- The process becomes overwhelming

RECOMMENDATIONS

(1). The financing system should be redesigned to eliminate existing inequities and irrationalities.

The redesign should satisfy at least these conditions:

(a) It should substantially increase the extent to which people have control of the money that pays for the assistance they need.

(b) It should substantially increase the flexibility with which funds can be used.

(2). The licensing system should be redesigned.

The redesign should satisfy at least these conditions:

(a) Through self-advocacy organizations, the people who use licensed services should play an active role in the redesign.

(b) The process must explicitly recognize that involved people must draw a balance between risk and opportunity rather than imposing a preemptive concern for safety, as safety is understood in general, by medically oriented personnel.

(c) The process must substantially decrease the deficit focus embodied in the current system.

(d) The process must substantially increase the flexibility of staff to respond to personal plans developed by concerned people.

(e) The process must be minimally intrusive on people's freedom to enjoy valued experiences.

(3). Greater flexibility in housing options

(a) Finalizing the downsizing/closure issue for freer movement out of ICF's

(b) Development of housing cooperative options

(c) Conversion/diversion availability

(d) Promoting consumer home ownership

(e) Avoid housing people by labels

(f) There are sufficient opportunities for assisting interested people with housing to justify funding a resource person who could help people understand the options and the procedures.

(4). Active state and county support of person-centered themes

(a) Systems management should consider taking the approach we are currently taking and make a statewide commitment to involvement of providers in all counties and county case management to person-centered themes.

(b) Outcome standards, quality criteria, and goal/objective development should be based on the "five valued experiences" (this would result in rule simplification).

(c) Annual planning and other processes should be based on celebration of people's strength, not a system based on their weakness and "fixing" things.

(5). That a steering/project committee be developed from the eight project agencies with state officials and DHS to tackle key issues and develop legislative proposals to enhance the person-centered approach.

The Person-Centered Agency Design Project was sponsored by the:

Human Services Research and Development Center
1195 Juno
St. Paul, Minnesota 55116
(612)698-5565

The project was funded by the Bush Foundation and the Hugh J. Andersen Foundation, and operated from September 1991 through September 1994. The eight participating agencies were:

Clay County Diversified Services, Inc.
Clay County Supported Training Services
123-1/2 21st Street South
Moorhead, MN 56560
218-233-8658
(residential and vocational/employment services in the Clay County area)

Cooperating Community Programs (CCP)--
Washington County
28770 Old Town Road
Stillwater, MN 55082
612-430-1597
(primarily waiver-funded and SILS residential services)

Dakota, Inc.
1380 Corporate Center Curve Suite 305
Eagan, MN 55121
612-454-2732
(vocational services in 9 programs in Hennepin and Dakota counties)

Houston County Group Homes
137 E. Main St.
Caledonia, MN 55921
507-724-3108
(ICF/MR, waiver, SILS, and other residential services throughout Houston County)

International Falls Group Home
(Lutheran Social Services)
2000 Spruce St.
International Falls, MN 56649
218-285-7264
(12-bed ICF/MR)

Linnea Residential Home, Inc.
14524 61st Street Court North
Box 450
Chisago City, MN 55013
612-257-2211
(12-bed ICF/MR)

MBW Company
1200 S. Broadway
New Ulm, MN 56073
507-354-3808
(ICF/MR, waiver, SILS and other residential services in several counties)

STEP, Inc.
703 Cory Lane
P.O. Box 110
Fairmont, MN 56031
507-238-4341
(day programs/supported employment in three centers in Fairmont and Blue Earth)

This project has received national and international attention. It was featured in "Reinventing Quality: A Sourcebook of Innovative Programs for Quality Assurance and Service Improvement in Community Settings" (Institute on Community Integration, University of Minnesota), the national newsletter of the American Association on Mental Retardation (AAMR), and national, regional, and state conferences of the Association for Persons with Severe Handicaps (TASH) and AAMR.

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"FAMILY TIES"

I, Ron Johnson, joined Dakota, Inc. Crystal in June of 1992 as a spring graduate (that's what they call us newcomers). I quickly became very popular with everyone due mostly to my rugged good looks, deep brown eyes, bright smile, and winning personality.

The staff person I was to train in was Terri. She seemed nice enough and I was hoping she would fulfill Dakota's promise of community integration and supporting me in finding friends. Believe it or not, with all the things I had going for me I had no family or friends. I only had people who were paid to be with me, and though I know they cared for and loved me, I still felt a void in my life. I spent the summer teaching Terri my likes and dislikes, and most importantly how I communicated them. I also got to know her and found that she was a pretty nice person too. Some of the things I taught her was that I was truly a "people person," the more attention I could get the better! She also figured out that I liked to talk on the phone - - I even enjoy leaving messages on people's answering machines. I also like funny interesting noises, they always make me want to smile and laugh.

Towards the end of summer, Terri introduced me to Stacey. She is the mother of another Dakota staff person and her job is to monitor families who do home schooling for their children, to make certain they are meeting the criteria set by the state. Stacey and I spent a little over a month getting to know each other. After that she decided she had a wonderful family for me to meet. This family consisted of Mark and Cheryl, Inga, Lynn and Hannah. It was just a coincidence that we shared the same last name; it was nice though, it gave us something in common immediately. Unfortunately, for myself and the Johnson family, I wasn't feeling very well when we first met. My weight had dropped and I was constantly fighting off some type of respiratory illness. I stopped smiling and laughing and my energy level had gone way down. But when I saw the Johnsons, I would follow the girls with my eyes and try to smile at their antics.

Through all the countless doctors and hospitalizations a way was discovered to ease my illness and help me on the road to good health. My various respiratory problems were caused by my aspiration of food into my lungs. A G-tube was put in place and I began receiving my meals in that way. I felt the change immediately. Not only did I regain my good health, but I put on some weight, my energy level was up and I became my smiling mischievous self again.

I'll never forget the first time I reached out my hand to Cheryl and said "Hi." I'm not sure who was more excited, Cheryl or Terri, and their excitement was contagious. Now when I visit with the Johnsons or when we go places together, I really participate, voicing my opinions, laughing when I find something funny, and letting everyone know when I'm bored. Three of my favorite things to do with the Johnsons are going for walks in the park, browsing through toy stores, and visiting them in their home. I truly enjoy visiting in their home the most. Inga and Lynn tell me how school is going and put on an occasional piano recital for me. All three share their toys with me, especially the ones that make funny noises. I get a special kick out of Hannah who enjoys imitating some of the noises I make. I even taught her how to do a "rasberry." I hope she doesn't do that one in church!

Recently I went on vacation to Florida where I went to Disney World. While there I picked up shell bracelets for Inga, Lynn, and Hannah as a token of how much their friendship means to me. I try to remember them on special occasions and holidays and they remember me too. The Johnson family has filled two voids in my life: giving me a family to love and becoming my true friends.

Dakota Inc. has come through on their promise to me, my life is pretty full now. I wonder if they could help me find a girlfriend . . since I don't drive it is hard to date, I wonder . . . . . .

- Ron Johnson, as written by Terri Anderson